

IT'S A MATCH! – FINDING THE PERFECT PARTICIPANTS FOR HEALTH RESEARCH. STUDY ON THE WILLINGNESS TO SHARE HEALTH DATA WITH A RESEARCH REFERRAL PORTAL

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Finding suitable participants is a big challenge for health research and is considered a significant barrier. Research referral portals (RRPs) matching participants with requirements of researchers are intended to overcome this barrier. Here, the willingness to share health data is the key success factor for this data-driven matching process. However, the variables and incentives influencing the willingness to share have not been researched in this specific context so far. Therefore, this article presents a two-stage study exploring individuals' willingness to share personal health data with RRP's conducting two focus group interviews (n=13) and an online survey (n=1,223). The study investigated the willingness to share data among individuals for RRP's and identified five influencing data categories. We also identified factors such as attitudes towards technology, altruism, and science affecting willingness to share. Practical implications include refining matching processes and enhancing data security, while longitudinal studies are suggested for broader insights.

Keywords:
healthcare data,
research referral portals,
matchmaking,
willingness to share health data

1 Introduction

Despite clinical research involving participants forming the backbone of our health system, finding suitable participants remains a major challenge for health research (Capili, 2021; Chaudhari et al., 2020; Gul & Ali, 2010). Finding suitable participants is not trivial as the participants must fulfill a study-specific set of inclusion and exclusion criteria such as age or specific diseases. The more specific these requirements are, the more challenging is it to find suitable participants (Capili, 2021; Evans & Ildstad, 2001). To start this recruitment process, a large amount of participants' health data is necessary. As this is challenging, the researchers may not be able to continue their project (Borg et al., 2024), slowing down health research. Research referral portals (RRPs) are one way to solve this major challenge, as they recruit participants for researchers and facilitate connecting participants, researchers, and research institutions. The major success factor of RRP is the availability of comprehensive health data about as many potential participants as possible. However, health data is considered sensitive and the willingness to share such data is limited (Woldaregay et al., 2020).

Previous research (e.g., Seltzer et al. 2019) indicates that individuals are already willing to share their health data with researchers, but the contexts in which they would be most likely to share data for research use is unclear. To date, comprehensive research investigating the dynamics between the matching process, willingness to share health data, and incentives remains notably scarce. While several studies (e.g., Broekstra et al., 2020; Singer & Couper, 2008; Song et al., 2023) have delved into the aspects of incentives of why individuals take part in clinical trials, a comprehensive understanding of how the elements interplay in the context of an RRP is yet to be clarified. This article aims to investigate the willingness of individuals to share their health data with RRP. It answers the following research question: *Which factors influence the willingness to share personal health data for matching participants with health studies?*

2 Background and Hypotheses

Clinical trials involving humans are an essential basis for scientific progress in medicine (e.g., the development of drugs), and therefore, it is necessary to find volunteering participants who agree to share health data (Inan et al., 2020; Tishler &

Bartholomae, 2002). There are several reasons why clinical trials might fail. The most common ones are issues with the study design, safety concerns, and insufficient funding, but one of the main hurdles is patient recruitment and retention (Fogel, 2018; Su et al., 2023). Challenges accompanying recruitment and retention are among others participant interest, inclusion and exclusion criteria, geographical barriers, or patient burden (Fogel, 2018; Kelly & Halabi, 2018). Participation in clinical trials provides several advantages for participants such as intensive monitoring, access to new drugs, or active contribution to medical research. However, the data collection in health care plays a crucial role and therefore cannot be overstated. Health data (e.g., electronic health records or patient/disease registries) affects every facet of the health care system, from health care providers to patients.

To close the gap between participants and studies, RRP's intervene and use a matching process, where they compare two sets of data and match them against each other (Integrate.io, 2023). This process is designed to refer participants to studies based on specified characteristics. It starts with the researchers specifying the inclusion and exclusion criteria and passing them on to the RRP (1). Then, the future participants share their health-related data with the RRP (2). The focus of this matching now lies on the user profile. This data is matched with the study requirements and potential matches are identified (3). Eligible users are now notified and invited to participate in the clinical trials. This process enables the RRP to find suitable participants for the studies, while the participants can participate in studies that match their needs and interests (see Figure 1).

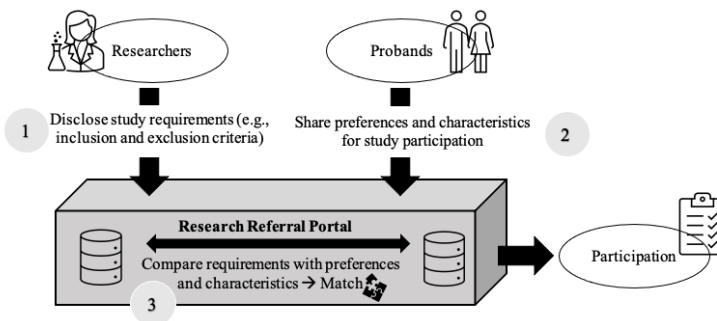


Figure 1: Matching Process of Research Referral Portals (RRPs)

Source: Own

Based on this matching process, an RRP is therefore a specialized online platform used to connect researchers and subjects (Integrate.io, 2023). Such portals enable researchers to conduct studies and collect health data from participants while allowing individuals to participate in these studies and potentially gain access to new treatments, medications, or monetary compensation.

Participants' motives and barriers for sharing personal health data for medical research influence their decision to share personal health data with an RRP (Broekstra et al., 2020; Permuth-Wey & Borenstein, 2009). The motives and barriers might explain differences between participation and non-participation, and therefore, it can be assumed that motives increase and barriers decrease the willingness to share personal health data. The literature distinguishes between two barriers to sharing personal data: (1) lack of individual benefits, and (2) non-contribution to public goods (Broekstra et al., 2020). The former describes the discrepancy between participants' expectations and the benefits offered. Participants would still become ill irrespective of their research participation, denoting a lack of individual benefit from a medical examination. Moreover, the time and effort invested in each study may be barriers to participation in general (Broekstra et al., 2020). The latter barrier describes the fear that their health data might be sold or misused, often driven by skeptical news, or negative experiences during previous research visits (Broekstra et al., 2020).

In the literature, three main motives for participating in health research are distinguished: altruism, survey-related, and egoistic reasons. Altruism describes a "behavior that benefits others at a personal cost to the behaving individual" (Kerr et al., 2004), e.g., donating a kidney (Lamanna, 1997). In the context of a health-related study, altruism means that the research furthers some purpose that is important to the participant, or the participant is fulfilling a social obligation (Singer & Couper, 2008). Survey-related reasons are aspects a participant is interested in, or they find the interviewer/researcher appealing (Singer & Couper, 2008), whereas egoistic reasons mean that the participant likes to participate or just participates for the money (Singer & Couper, 2008). Even though monetary benefits are often used and mentioned as an effective incentive for research participation, there are still other approaches (e.g., curiosity, scientific advancement, and desire for medical care/attention) to increase the willingness to share data and thus obtain sufficient participants for research (e.g., Permuth-Wey and Borenstein 2009).

Since various factors, i.e., attitudes, might contribute to a variability in decisions regarding private data (Woldaregay et al., 2020). In this article, we investigate how different attitudes influence the willingness to share health (WILL). We assume that different attitudes influence people's decisions regarding sharing their health data, since they seem to be essential for health research, facilitating informed decision-making, fostering participation, and ensuring the advancement of medical research for societal benefit (Colombo et al., 2019; McCormack et al., 2016). Those three are attitudes towards technology (ATTT), attitudes towards altruism (ATTA), and attitudes towards science (ATTS).

ATTT: As technology drives growth and economic development, the impact of technology appears to have a heavy impact on society (R. Williams & Edge, 1996). The ATTT can be defined as an individual's positive or negative evaluation of the introduction of new kinds of technology in an individual's life (Elias et al., 2012). Kim and Choi (2019) concluded that individuals with a positive ATTT are more willing to share their socio-economic and health data with hospitals and researchers. Also, individuals with experience with information technology are more willing to share their health data (Naeem et al., 2022). Since this attitude seems to affect an individual's mindset, it can be assumed that the ATTT might also affect the decision to share health data with RRP. Thus, we formulated the following hypothesis: ***H1: The higher the attitude towards technology, the higher the willingness to share health data.***

ATTA: Altruism represents one of the main concepts when sharing data. In the context of a health-related study, altruism means that the research furthers some purpose that is important to the participant, or the participant is fulfilling a social obligation (Singer & Couper, 2008). According to Manzur & Olavarrieta (2021), there exist several studies about the individual differences in altruistic behavior with different groups of people (adults, children, different countries, etc.). Studies suggest that although willingness to join multi-user data networks is low, altruism significantly predicts participation in such networks (Raj et al., 2020), reinforcing the notion that ATTA influence willingness of sharing data. Given this background, we assume that the altruistic attitude of a person influences the willingness to share health data positively: ***H2: The higher the attitude towards altruism, the higher the willingness to share health data.***

ATTS is composed of six dimensions that affect behaviors in science: “[...] attitude toward scientists, scientific enquiry, science learning, science-related activities, science careers, and the adoption of ‘scientific attitudes’” (Mao et al., 2021). Prior research, such as Jamal et al (2014), has shown that high trust in researchers influences the willingness to share personal data positively, since participants feel engaged with researchers and valued. Therefore, a positive ATTS is an indicator of a high willingness to share data. Given this background, we assume the following hypothesis: **H3: The higher the attitude towards science, the higher the willingness to share health data.**

In addition to ATTS, research on experience of clinical trial participation indicates that as soon as individuals have participated in health-related studies, they gain more trust in such study designs (Ohmann & Deimling, 2004). The concept and building of trust can be explained by the easy, accessible, and feasible sharing of health data (Naeem et al., 2022). Several studies indicate that the higher the level of trust, the more likely individuals will be willing to share data in the future (Naeem et al., 2022). Thus, we investigate the influence of earlier participation and formulated the following hypothesis: **H4: Earlier participation in studies increases willingness to share data.**

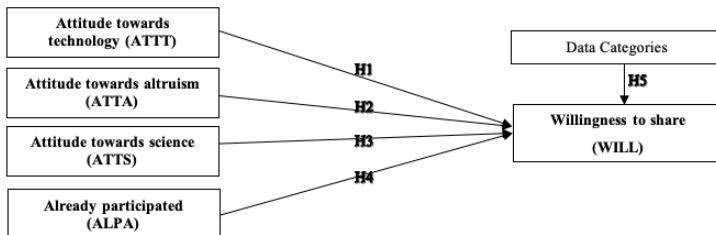


Figure 2: Hypothesis Model
Source: Own

Not only the fundamental willingness to share data (WILL) is assumed to be influenced by attitudes. According to Naeem et al. (2022), the category of health information influences the willingness to share data. Hirst et al. (2023)’s study showed differences between the willingness to share different types of data, while Woldaregay et al. (2020) concluded that health data sharing depends on the type of data. Therefore, we assume that the data categories influence the willingness to

share health data in a moderating way: ***H5: The data category influences the willingness to share.***

3 Method and Procedure

We conduct a two-stage study consisting of two focus groups and an online survey to investigate the willingness to share health data.

Stage 1 – Workshops: Data categories and incentives for sharing health data with RRP were identified in two separate workshops in March 2023 for participants who were registered at an RRP (n=7) and those who were not (n=6). Both workshops were designed equally and consisted of brainstorming, clustering, prioritization, and an in-depth discussion regarding the data categories and incentives. Both workshops were audio-recorded, transcribed, and analyzed using the thematic analysis by Braun and Clarke (2006).

Stage 2 – Survey: Building on the data categories identified in the workshops, we conducted an online survey via LimeSurvey to test the hypotheses. We recruited our participants via the university distribution mail for student surveys, via social media platforms, and via NORSTAT. A total of 2,966 persons participated in the survey, whereby 1,743 participants had to be excluded due to incomplete or insufficient datasets. Thus, our final sample consisted of 1,223 participants. The age distribution of participants varied: 5.40% were aged 19 or younger, 18.32% were between 20 and 29 years old, 17.01% fell within the 30-39 age bracket, 15.37% were aged 40-49, 17.58% were between 50-59, 13.00% were in the 60-69 range, and 12.10% were 70 or older. Regarding gender distribution, 53.36% identified as female, 46.07% as male, and 0.41% as diverse; 3 participants did not specify. Educational backgrounds varied, with 33.14% completing middle or high school, 31.75% completing apprenticeships, and 22.50% holding university degrees. Employment status was diverse: 43.4% were employed full-time, 24.8% part-time, 12.4% marginally employed, 1.8% unemployed, 5.3% self-employed, 7.1% retired, and 5.3% unable to work. Notably, 3.19% did not understand the matching process. In terms of research experience, 41.09% had participated in research studies before, while 58.91% had not.

Procedures and data collection: The online survey was structured the following way: The matching process was explained using visualizations and participants were asked whether it had been understood. If it was not understood, only the demographic information was requested. If the participants understood the process, the willingness to share data (WILL) was asked, and which clients were excluded. Next, we asked for each data group (e.g., health status) how easy it is for them to share a certain data group with an RRP and how they assess which motives influence their motivation and to what extent. Motives extracted from the literature and discussed in the workshops were questioned: monetary compensation, general interest, medical progress, and individual treatment. Finally, attitudes towards three topics were queried, i.e., technology, altruism, and science. The questionnaire was pre-tested by six people with different backgrounds (business analytics, languages, business administration). The survey was released on May 17, 2023, and ended on August 17, 2023.

Measures: All items were answered on a Likert scale ranging from (1) “Fully agree” to (5) “Do not agree at all”. *ATTT* measured the average attitude of a person towards technology using the 10-item construct by Edison and Geissler (2003). *ATTA* measured an individual’s attitude towards altruism and sociality using the 9-item construct from Manzur and Olavarrieta (2021). *ATTS* measured participants’ attitude towards science using the 21-item construct by Akkuş (2019). *Willingness to share data (WILL)* measured the preferences of participants regarding sharing personal health data.

4 Results

We identified five data categories relevant to a well-performing matching process of RRP: (1) health status, (2) attested diseases, (3) current medication, (4) mental health, and (5) lifestyle habits. Our findings show that the willingness to share data differs depending on the data category.

Health status: Health status describes a person’s medical conditions, health care, medical history, as well as genetic information (e.g., World Health Organization, 2023). Overall, sharing data about the category health status with RRP seems not to be a big deal for the individuals, “*I would disclose the health data immediately, I don’t need anything in return. It would be cool to receive a report of the results directly [...].*” (I10).

However, participants presuppose that it should not be of great effort to share this kind of data; it should be time-saving to share it with RRP. Here, the more time they have to spend sharing that data, the higher should be the remuneration; participants want to receive some reward in exchange for this data as one participant explained, *“The longer [the data input] lasts, the more intense it is, the more effort there is behind it, [I would want to receive] some form of compensation.”* (I6)

Attested diseases: A disease is a condition of the living body or of its parts that impairs normal functioning and is typically shown by distinguishing symptoms (Amzat & Razum, 2014). The participants subdivided this data category into two subgroups, namely mild and severe diseases. One can also interpret severe diseases as sensitive; diseases that are e.g., embarrassing for the participants. In principle, participants are easily willing to share data on attested diseases, however, their willingness decreases the more severe the disease is. Given this background, individuals would be willing to share mild diseases without any problems or incentives. In contrast, in the case of severe diseases, individuals are more likely to be unwilling to share these data, or they demand to receive some sort of monetary reimbursement or individual treatment, *“[...] differentiate between different diseases, i.e., serious diseases such as leukemia, cancer, and other diseases. I would easily give that away to speed up treatment or to advance research. And yes, because such minor illnesses and so on, that is simply visual impairment or something like that, then perhaps probably monetary compensation, but also to advance research.”* (I9)

Current medication: Regarding this data category, participants are concerned about the risk of data breach, resulting in a low willingness to share this type, *“But that often changes so quickly. And then the question arises of how up to date this list is.”* (I6). Due to their concerns regarding data protection, participants generally expect to receive monetary reimbursement for sharing information within this data category. However, some participants noted that they would share this data freely to advance research.

Mental health: This category is alone standing as Amzat and Razum (2014) clearly distinguish mental health from physical health. In general, participants are reluctant to share information about their mental health. Their reluctance is reflected in a low willingness to share this data, as the following statement indicates, *“And when it comes to mental health, I find that difficult because there's a stigma here and it's often not easy, so I would find that difficult.”* (I4). Having these concerns in mind, participants seemed to need

to get a feeling that this personal data is being treated and processed confidentially. They want to advance research and create sensitivity by sharing their data.

Lifestyle habits: This category covers personal interests and preferences, which are directly connected to a person's health status, e.g., attitudes towards alcohol and smoking, drug use, sports activities, or nutrition (Mozaffarian et al., 2008). Individuals are willing to share information about their lifestyle habits without any problems, and any kind of remuneration or incentive. However, some of the participants could imagine receiving little monetary reimbursements, such as coupons or discounts, "*Lifestyle habits – I have no problem at all.*" (I3)

Overall, it seems that the participants either want to advance research in return for their data sharing or they want to receive monetary benefits for doing so. Table 1 displays an overview of the identified data categories as well as the respective incentives to increase individuals' willingness to share data belonging to one of the respective data categories.

Descriptive results: Table 1 shows means and medians for all variables. In general, the participants showed a high willingness to share data. Of the final sample, 44.51% fully agreed and 43.83% agreed to share data. Only a small percentage disagreed or strongly disagreed, with 1.44% indicating they did not agree at all. Besides a high willingness to share data, participants showed a positive ATTT, ATTA, and ATTS. Here, mean values range from 2,988 for ATTA to 3,798 for ATTS. Concretely, individuals have a moderately positive ATTT, as indicated by a mean of 3.686. The median of 3.800 shows that half of the participants fall below this score, and the other half above it. Similar to ATTT, participants also hold a moderately positive outlook on ATTA (mean value=2.988). The median of 2.889 signifies that half of the respondents have attitudes towards altruism lower than this score, and the other half above it. In contrast, ATTS appears quite positive with a mean score of 3.798. The median of 3.810, indicates that half of the participants have an attitude towards science lower than this score, while the other half have attitudes above it.

Table 1: Descriptive Results

	ATTT	ATTA	ATTS	WILL
Mean	3.686	2.988	3.798	4.274
Median	3.800	2.889	3.810	4.000

Correlation analysis: We conducted a correlation analysis using Pearson correlation tests to test our hypotheses that, a higher attitude towards technology (H1), a higher attitude towards altruism (H2), and a higher attitude towards science (H3) lead to an increased willingness to share health data. In addition, we also investigated the willingness to share different data categories (H5). These tests assume that the variables are normally distributed; this is significantly ensured with the collected data. Additionally, we conducted a Mann-Whitney-U-test to investigate whether earlier participation in studies influences the willingness to share data (H4). Table 2 summarizes the correlations and the corresponding p-values of the hypothesis tests. The correlation value between ATTT and WILL is **0.216903**, which shows a weak but still positive correlation. The p-value indicated in Table 2 is much lower than the assumed significance level of 0.05. The results suggest that a positive ATTT is associated with an increased WILL. Therefore, our results support H1. The correlation between ATTA and WILL is calculated as **0.17155**. As expected, this value is positive but quite weak. Thus, as previously assumed, the altruistic behavior of individuals represents an important and influences the willingness to share private health data. Our results support H2. The correlation between ATTS and WILL is **0.200791**, indicating a small positive correlation. As a result, the attitude towards science positively influences the willingness to share data. Thus, H3 is supported.

The mean of people who have already participated (ALPA) in clinical trials is 4.35, and the mean of people with no experience is 4.22. This significant (p-value **0.02394**) result indicates that individuals with experience are more willing to share their health data with an RRP compared to individuals with no experience. It can be assumed that WILL is significantly higher in experienced than in non-experienced participants. Thus, the results support H4. Our findings show that ATTT positively influences WILL but also the data categories' willingness to share certain data. We observed only minor differences between the data categories. Here, only WILL about current medication is clearly smaller than the other correlations. Similar to ATTT, ATTA also positively influences WILL. However, it less influences different

data categories (see Table 2). Individuals' ATTS also positively influences WILL. It is noticeable that the correlation between ATTS and the willingness to share lifestyle habits is quite high. The positive correlations of all variables (see Table 2) support H5.

Table 2: Correlation Matrix towards willingness to share data (WILL)

	WILL	WILL Health S.	WILL Current M.	WILL Attested D.	WILL Mental H.	WILL Lifestyle H.
ATTT	0.216903 (0.000000 00000002 251)	0.1748014 (0.0000000 007013)	0.1670655 (0.00000000 3664)	0.2120066 (0.00000000 000008452)	0.1802049 (0.0000000 002114)	0.2122917 (0.00000000 000007833)
ATTA	0.17155 (0.000000 001417)	0.1485261 (0.0000001 42)	0.1353442 (0.00000147 9)	0.1612933 (0.00000001 198)	0.1655567 (0.0000000 05014)	0.1539476 (0.00000005 092)
ATTS	0.200791 (0.000000 00000155 2)	0.2200518 (0.0000000 000000094 51)	0.2375699 (0.00000000 000000022)	0.1965512 (0.00000000 0004467)	0.1939512 (0.0000000 00008443)	0.3143476 (0.00000000 000000022)

5 Discussion and Outlook

We investigated the willingness of people to share health data needed for the matching process of RRP. By doing so, we conducted a two-stage study that consisted of focus group workshops and an online survey to explore data categories and incentives for sharing health data with RRP. This study makes two **key contributions to both practice and theory**: First, we contribute to the research on willingness to share data by identifying and validating those data categories relevant for sharing data with RRP. We identified five data categories influencing the willingness to share: health status, attested diseases, current medication, mental health, and lifestyle habits based on the literature. Here, our findings indicate that participants' willingness to share data could be influenced by different incentives such as monetary reimbursement or altruism. Our findings are consistent with previous studies such as Woldaregay et al. (2020) who highlight that participants' willingness to share their diseases depends on different attitudes. Participants expressed a higher willingness to share mild diseases compared to severe ones, with

a preference for rewards or individual treatment in the case of more serious diseases - concerns about data breaches and the changing status of current medication led to a lower willingness to share this category, often entailing monetary reimbursement. Mental health data raised reluctance, highlighting the need for confidentiality and a sense of trust. Lifestyle habits, on the other hand, were readily shareable without specific incentives. These results confirm that there are differences in the willingness to share data for different data categories shown in traditional settings (e.g., Hirst et al. 2023). Second, we contribute to the understanding of factors influencing data sharing by demonstrating the effects of various attitudes on the willingness to share data in the specific context of RRP. Our study reveals that a positive attitude towards technology increases the willingness to share data. Thus, we show that this relationship holds also in the context of RRP. Kim and Choi (2019), which showed its impact on society and thus the individual mindsets about sharing private health data with research portals. Similarly, Broekstra et al. (2020), for example, highlighted that individuals consider participation in research to promote social progress and therefore see the sharing of health data as a donation. Moreover, our findings support Jamal et al.'s (2014) assumption that a positive attitude towards science is correlated with an increased willingness to share personal data for the context of RRP. Like Naeem et al. (2022), our study revealed that participants with previous research experiences were found to be more willing to share their health data than those without.

From a practical perspective, RRP now can build upon these results and differentiate their data collection. Understanding the willingness to share health data across categories allows for the development of targeted strategies, ensuring more effective participant recruitment for health studies and clinical trials. Such a data-driven approach, as this is with a customized data collection combined with the identified incentives, seems very promising (Huang et al., 2018). Current research (e.g. Woldaregay et al. 2020) highlighted the need for strict privacy measures in traditional study context. Participants also found such concerns about data protection, especially regarding the data categories of current medication and mental health data, which is consistent with Woldaregay et al.'s (2020) results, emphasize the need for robust privacy measures in the context of RRP. Thus, the focus on implementing and communicating strict data protection protocols to build trust among potential participants seems a key success factor for RRP.

Our study has one major **limitation**: All participants came from Austria. Nevertheless, the participants were of varying professional and cultural backgrounds and age ranges. It might be interesting to build on our results and research in other countries and world regions. Furthermore, our findings can serve as a starting point for future research on the willingness to share health data. By including perspectives from individuals who avoid data sharing, future studies could offer a fuller understanding of participation barriers. We encourage researchers to conduct longitudinal studies to explore how attitudes towards technology, altruism, and science evolve over time could provide a deeper understanding of the factors influencing individuals' willingness to share health data. This could contribute to the development of more dynamic and adaptive participant recruitment strategies.

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References

- Akkuş, A. (2019). "Developing a Scale to Measure Students' Attitudes toward Science", *International Journal of Assessment Tools in Education*, 6, 706–720.
- Amzat, J. and Razum, O. (2014). "Health, Disease, and Illness as Conceptual Tools", *Medical Sociology in Africa*, 21–37.
- Borg, D. J., Haritopoulou-Sinanidou, M., Gabrovská, P., Tseng, H.-W., Honeyman, D., Schweitzer, D., & Rae, K. M. (2024). Barriers and facilitators for recruiting and retaining male participants into longitudinal health research: A systematic review. *BMC Medical Research Methodology*, 24(1), 46.
- Braun, V. and Clarke, V. (2006). "Using thematic analysis in psychology", *Qualitative Research in Psychology*, 3, 77–101.
- Broekstra, R. et al. (2020). "Motives of contributing personal data for health research: (non-)participation in a Dutch biobank", *BMC Medical Ethics*, 21, 62.
- Capili, B. (2021). Selection of the Study Participants. *The American Journal of Nursing*, 121(1), 64.
- Chaudhari, N., Ravi, R., Gogtay, N. J., & Thatte, U. M. (2020). Recruitment and retention of the participants in clinical trials: Challenges and solutions. *Perspectives in Clinical Research*, 11(2), 64–69.
- Colombo, C., Roberto, A., Krleza-Jeric, K., Parmelli, E., & Banzi, R. (2019). Sharing individual participant data from clinical studies: A cross-sectional online survey among Italian patient and citizen groups. *BMJ Open*, 9(2), e024863.
- Edison, S.W. and Geissler, G.L. (2003). "Measuring attitudes towards general technology: Antecedents, hypotheses and scale development", *Journal of Targeting, Measurement and Analysis for Marketing*, 12(2), 137–156.
- Elias, S.M., Smith, W.L. and Barney, C.E. (2012). "Age as a moderator of attitude towards technology in the workplace: work motivation and overall job satisfaction", *Behaviour & Information Technology*, 31(5), 453–467.
- Evans, C.H. and Ildstad, S.T. (eds) (2001). *Small Clinical Trials: Issues and Challenges*. Washington (DC): National Academies Press (US).

- Fogel, D.B. (2018). "Factors associated with clinical trials that fail and opportunities for improving the likelihood of success: A review", *Contemporary Clinical Trials Communications*, 11, 156–164.
- Gul, R.B. and Ali, P.A. (2010). "Clinical trials: the challenge of recruitment and retention of participants", *Journal of Clinical Nursing*, 19(1–2), 227–233.
- Hirst, Y. et al. (2023). "Understanding Public Attitudes and Willingness to Share Commercial Data for Health Research: Survey Study in the United Kingdom", *JMIR Public Health and Surveillance*, 9(1), e40814.
- Huang, G.D. et al. (2018). "Clinical trials recruitment planning: A proposed framework from the Clinical Trials Transformation Initiative", *Contemporary Clinical Trials*, 66, 74–79.
- Inan, O. T., Tenaerts, P., Prindiville, S. A., Reynolds, H. R., Dizon, D. S., Cooper-Arnold, K., Turakhia, M., Pletcher, M. J., Preston, K. L., Krumholz, H. M., Marlin, B. M., Mandl, K. D., Klasnja, P., Spring, B., Iturriaga, E., Campo, R., Desvigne-Nickens, P., Rosenberg, Y., Steinhubl, S. R., & Califf, R. M. (2020). Digitizing clinical trials. *Npj Digital Medicine*, 3(1), 1–7.
- Integrate.io (2023). What is Data Matching? URL: <https://www.integrate.io/glossary/what-is-data-matching/> (visited on November 9, 2023).
- Jamal, L. et al. (2014). "Research participants' attitudes towards the confidentiality of genomic sequence information", *European Journal of Human Genetics*, 22(8), 964–968.
- Kelly, W. K., & Halabi, S. (2018). *Oncology Clinical Trials: Successful Design, Conduct, and Analysis*. Springer Publishing Company.
- Kerr, B., Godfrey-Smith, P., & Feldman, M. W. (2004). What is altruism? *Trends in Ecology & Evolution*, 19(3), 135–140.
- Kim, T.K. and Choi, M. (2019). "Older adults' willingness to share their personal and health information when adopting healthcare technology and services", *International Journal of Medical Informatics*, 126, 86–94.
- Lamanna, M.A. (1997). "Giving and getting: altruism and exchange in transplantation", *The Journal of Medical Humanities*, 18(3), 169–192.
- Manzur, E. and Olavarrieta, S. (2021). "The 9-SRA Scale: A Simplified 9-Items Version of the SRA Scale to Assess Altruism", *Sustainability*, 13(13), 6999.
- Mao, P. et al. (2021). "The Relationship Between Attitude Toward Science and Academic Achievement in Science: A Three-Level Meta-Analysis", *Frontiers in Psychology*, 12.
- McCormack, P., Kole, A., Gainotti, S., Mascalzoni, D., Molster, C., Lochmüller, H., & Woods, S. (2016). 'You should at least ask'. The expectations, hopes and fears of rare disease patients on large-scale data and biomaterial sharing for genomics research. *European Journal of Human Genetics*, 24(10), Article 10.
- Mozaffarian, D., Wilson, P.W.F. and Kannel, W.B. (2008). "Beyond established and novel risk factors: lifestyle risk factors for cardiovascular disease", *Circulation*, 117(23), 3031–3038.
- Naeem, I. et al. (2022). "Factors Associated With Willingness to Share Health Information: Rapid Review", *JMIR Human Factors*, 9(1), e20702.
- Ohmann, C. and Deimling, A. (2004). "Attitude towards clinical trials: results of a survey of persons interested in research", *Inflammation Research: Official Journal of the European Histamine Research Society ... [et Al.]*, 53 Suppl 2, S142-147.
- Permeth-Wey, J. and Borenstein, A.R. (2009). "Financial Remuneration for Clinical and Behavioral Research Participation: Ethical and Practical Considerations", *Annals of Epidemiology*, 19(4), 280–285.
- Raj, M., Vries, R. D., Nong, P., Kardia, S. L. R., & Platt, J. E. (2020). Do people have an ethical obligation to share their health information? Comparing narratives of altruism and health information sharing in a nationally representative sample. *PLOS ONE*, 15(12), e0244767.
- Seltzer, E. et al. (2019). "Patients' willingness to share digital health and non-health data for research: a cross-sectional study", *BMC Medical Informatics and Decision Making*, 19(1), p. 157.

- Singer, E., and Couper, M.P. (2008). "Do incentives exert undue influence on survey participation? Experimental evidence", *Journal of empirical research on human research ethics: JERHRE*, 3(3), 49–56.
- Song, X., Mehrotra, M., & Rajapakshe, T. (2023). An Analysis of Incentive Schemes for Participant Retention in Clinical Studies. *Manufacturing & Service Operations Management*, 25(3), 1033–1050.
- Su, Q., Cheng, G., & Huang, J. (2023). A review of research on eligibility criteria for clinical trials. *Clinical and Experimental Medicine*, 23(6), 1867–1879.
- Tishler, C.L. and Bartholomae, S. (2002). "The recruitment of normal healthy volunteers: a review of the literature on the use of financial incentives", *Journal of Clinical Pharmacology*, 42(4), pp. 365–375.
- Williams, R. and Edge, D. (1996). "The Social Shaping of Technology", *Research Policy*, 25, 865–899.
- Woldaregay, A.Z. et al. (2020). "User Expectations and Willingness to Share Self-Collected Health Data", *Stud Health Technol Inform*, (270), 894–898.
- World Health Organization (2023). Constitution of the World Health Organization. URL: <https://www.who.int/about/accountability/governance/constitution> (visited on November 17, 2023).